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AUTHOR Hurtig, Anita Landau; Koepke, David
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ABSTRACT

The study examined the effects of social support and family functioning on illness and adjustment in 70 children and adolescents with sickle cell disease. Four sources of information were used: patient interview and standardized tests; parent interview and standardized tests; teacher interview; and medical records. Results revealed several significant correlations between the child's report of family climate and the child's adjustment. As hypothesized, family environment and family/social support significantly affected the children's adjustment. The role of social support was less clearcut. The hypothesis that illness severity and familial/social forces would be closely related was generally weakly supported. It is concluded that data supports the clinical wisdom which recognizes the crucial role of social/family factors in children's adaptation to the illness. Nine slides shown during the presentation are appended. (CL)

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RELATIONSHIP BETWEEN ILLNESS SEVERITY, SOCIAL/ FAMILIAL VARIABLES AND ADJUSTMENT IN CHILDREN AND ADOLESCENTS WITH SICKLE CELL DISEASE[1]

Anita Landau Hurtig, Ph.D.

David Koepke, Ph.D.

University of Illinois at Chicago

Department of Pediatrics

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Relationship between Illness Severity, Social/ Familial Variables and Adjustment in Children and Adolescents with Sickle Cell Disease

Sickle cell anemia is the most prevalent chronic illness of children, adolescents, and adults in the black community, affecting one in every 400 to 500 black children. The characteristic and associated features of sickle cell disease represent high risk factors in terms of the normal developmental processes for children and adolescents. These features include pain episodes, often frequent and intense, as well as accompanying illness, behavioral and physiognomic concommitants such as severe infections, stroke, spleen and kidney involvement, growth delay, enuresis, priapism and others. The degree to which sickle cell disease children and adolescents are vulnerable to disturbances in adjustment has been reported (Hurtig and White, 1986; Lemanek, et al., 1986; Morgan and Jackson, 1986). Hypothesizing that the poorer adjustment of sickle cell children and even more significantly adolescents, might be a function of the specific nature and severity of their illness, Hurtig and Koepke (1986) found that severity aspects account for a very small amount of the variance in adjustment levels. They concluded that socio-environmental variables might be more important contributors to the impact of the illness on the emotional and behavioral development of the young sickle cell patient. Socioeconomic status, life stress events, social supports, and family characteristics were seen to be potential mediators between the disease process itself and the psychosocial effects of the disease on the child.

The role of socio-environmental factors in the somatic and adjustment aspects of the chronically ill has been studied from a number of different perspectives. Family functioning has been evaluated in terms of its mediating influence on the chronically ill child's adjustment to illness (Drotar, 1981; Anderson & Auslander, 1980; Pless, 1979; Wertleib, et al., 1986). Specific illnesses have been investigated, including diabetes, asthma, and cystic fibrosis. In their study of cystic fibrosis and asthmatic children, Lewis & Khaw (1982) reported higher levels of behavior symptoms in the chronic illness groups as compared to healthy children, but found these differences no longer significant where family functioning variables (adaptability and cohesiveness) were controlled for, leading to the conclusion that family functioning is an important mediator of adjustment to chronic illness. Other studies have implicated a range of family characteristics in the positive and negative adaptation of chronically ill children. A significant relationship between self-esteem and maternal warmth and control was found in a group of diabetic children, and organizational, independence and social/recreational orientations in the families of diabetic adolescents were associated with perceived competence and diabetic adjustment.

Social supports have also been studied in terms of their effect on susceptibility to physical and psychological symptomatology. Haggerty (1984) in his review of the life stress, social support and illness literature, concluded that social supports, defined as "connectedness with other humans", function as a protective factor against the effect of stress on illness. Empirical studies have not, however, conclusively supported this theory. In a recent review of the adult literature on stress, social support and physical

health, Wallston, et al. (1983) concluded that research evidence supporting a significant relationship between social support and physical health is not as clear-cut as previous reviews had claimed.

While social support and family functioning have been studied in relationship to illness variables in general, and to a few specific chronic illnesses, there have been no empirical studies which have considered the interaction of these two variables with illness and adjustment in sickle cell disease children. The significant role of the family and social-environmental forces in the impact of the disease has been theoretically formulated by Anderson & Slaughter (1986, 1985) but as yet empirical studies have not been reported.

In this study three hypotheses are investigated: 1 - that social support and family climate will significantly impact on the adjustment of pediatric sickle cell disease patients, 2 - that these variables will also have a significant effect on the illness severity experience of these patients, and 3 - that these correlations will exist across socioeconomic groups.

Method

Subjects

Subjects were drawn from the population of sickle cell disease children and adolescents who are serviced by the University of Illinois at Chicago, Department of Pediatrics Hematology-Oncology Clinic, and the Hematology Section of Children's Memorial Hospital, Chicago. All subjects were diagnosed as having sickle cell disease and all were free of developmental disabilities or other chronic illness. Subjects ranged in age from 8 through 16 years.

Seventy protocols were completed, - 33 males, 37 females. Thirty-eight were between 8 and 11 years of age and 32 between 12 and 16. Sixty five of the patients were Black, 3 Italian and 2 South or Central American. All families seen in the clinics with children with known sickle cell disease in the required age range were contacted by letter, informed of the nature of the study, and given a consent form to sign. Eight-three families were contacted at both sites: 70 agreed to participate. Each family received $35.00 to cover expenses. Three per cent were from non-parent homes, 37% were two parent households, 60% single parent households. Socioeconomic status ranged across all classes I through V, based on Hollingshead & Redlich (1957) Social Class Categories with 54% of the families in the lowest SES group (V), 78% in the two lowest categories (IV and V), 10% in the two highest categories.

Materials:

Four sources of information were utilized: patient interview and standardized tests, parent interview and standardized tests, teacher interview, and medical records. Subjects' reports included a structured interview with questions about home life, school life, social life and impact of and knowledge about sickle cell disease. The patients were also given the California Test of Personality, which offers scores of Personal and Social Adjustment, the Piers-Harris Self-Concept Scale and the child's report on the Family Environment Scale - a 90 item self-report, true-false instrument which looks at the interpersonal interactions described as characteristic of their families. There are 10 sub-scales: including Cohesion, Expressiveness, Conflict, Independence, Achievement and others. The children were also

administered the short form WISC-R. Parents' reports included a structured interview which asked about child's medical condition, home life, school life, social life, perceived effects of sickle cell disease and illness severity, and questions such as total number of hospitalization and emergency room visits from birth to present. The parents also completed the Child Behavior Checklist - Revised, which provides a level of social competence, reflecting activities, peer relationships and school functioning, as well as behavior problems, divided into two "broad band" groupings: Internalizing and Externalizing behaviors and a range of "narrow band" factors such as depression, withdrawal, somatic symptoms, impulsivity, hyperactivity, and others. Parents also filled out the Family Environment Scale.

Teacher reports were replies to a questionnaire sent to each subject's classroom or homeroom teacher, asking about academic performance, school and social life, and the effects of sickle cell disease on each. Teacher reports were available from 50 of the 70 subjects.

Medical records provided information on frequency of hospitalization and E.R. visits, onset of disease and type of hemoglobinopathy.

Slide 1 Dependent variables were illness severity and adjustment. Illness severity measures used were frequency and intensity of pain crises, total number of hospitalizations and emergency room visits for the most recent four year period for each subject, and age at diagnosis. Frequency of pain crises was calculated as the mean of parent and child report, which correlated .49. Pain intensity was based on child report. Adjustment was based on 9 measures: intellectual achievement, social competence, internalizing and externalizing

behavior problems, personal and social adjustment, self-concept and school performance and quality of peer relations. Subject's school performance was a composite measure of the ratings of parent, child and teacher. All of the ratings intercorrelated at significance levels of .05 or less. Quality of peer relations was also a composite measure of parent, child and teacher ratings. Correlations among these three ratings was somewhat lower ($p < .10$).

Intercorrelation between the adjustment measures were significant for 25 of the 36 pairs; all but one were in the expected direction. The adjustment variables will be reported separately because they represent different aspects of adjustment.

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Independent variables included family style or climate, as measured by the Family Environment Scale; family type: single-parent, married couple, step-parents, foster family or grandparent home; family-income type: working father, working mother, public assistance, disability; support system utilization: immediate nuclear family only, extended family, medical or social service personnel or none; and caretaker of child when ill: parent, alternative immediate family member, extended family member, neighbor and amount of time spent alone when ill. Three subject variables were also analyzed: age, sex and SES.

Results:

No significant differences were found for either sex or age. Therefore, the data will be presented for the total sample.

Slide 3

Looking at the mean and standard deviations of the child and parent FES scores as compared to the standardization sample, we find that in most areas

the sickle cell sample is comparable to the normative sample. Only moral/religious orientation and control show differences from the normative sample, in both cases significantly higher.

Adjustment Variables.

In terms of the relationship between adjustment variables and family organization, we find a number of significant correlations between the child's report of family climate and the child's adjustment. Cohesion in a family

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has significant positive relationships with child's self-concept, personal and social adjustment. Family independence relates significantly to self concept and personal adjustment and to intellectual achievement. Family intellectual/ cultural orientation relates significantly to self concept, social adjustment, school performance and intellectual achievement. An active/recreational orientation correlates with the greatest number of adjustment measures, specifically, self concept, social competence, personal and social adjustment and intellectual achievement. A moral/religious orientation correlates with self concept and personal adjustment. Organization in the family relates to self concept, social adjustment and school performance. Control relates to intellectual achievement. The only family dimension which showed a significant negative correlation with adjustment variables was conflict. Higher levels of conflict in the family accompany lower levels of self concept and personal and social adjustment. Based on child and adolescent perceptions, there was no relationship between family climate and behavior problems as measured by the CBCL.

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As shown in Table 2, the parent perception of family climate shows fewer relations to measures of child and adolescent adjustment. As with the children's report, conflict is the only family domain to correlate negatively with adjustment, specifically peer relations and school performance. Both parents' and patients' reports indicate no significant relationship between Expressiveness or drive toward Achievement and adjustment.

Slide 6

In looking at the nature of the family organization and support system utilized by the family, and adjustment variables in the patient, we find few significant correlations. Those children whose families report no social support system show negative correlations with many adjustment variables, but with the exception of personal adjustment, the significant levels fail to reach .05. Personal adjustment is higher in families where other relatives beside immediate family offer support (usually grandmother or aunt). Self concept is lower in patients whose families find support in church and in reaching out to parents of other sickle cell disease children. School performance is lower when "other" sources of support are noted; these include primarily "friends", "social workers", and "God".

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The nature of the caretaking experience when the child or adolescent is ill also shows a few significant correlations with adjustment variables. Patients who indicate that they spend a great deal of time alone when not in school, show lower levels of personal ($p < .01$, $r=-.34$) and social adjustment ($p < .01$, $r=-.32$). Patients who are cared for by relatives other than immediate family members (again, usually grandmother or aunt) show higher levels of self-concept and social adjustment ($p < .05$), while caretaking by an immediate family member other than parent (primarily siblings) shows a

significant correlation with externalizing behavior problems ($p < .01$) and a trend toward significant negative correlations with self-concept and personal adjustment ($p < .10$), and towards more internalizing behavior problems ($p < .06$).

Illness Severity Variables: The frecuency of correlations between illness severity variables and family structure, as reported by parents, is very small. Cnly Active/Recreational orientation consistently relates to these illness factors, specifically frequency of hospitalizations, E.R. visits and pain crises. Cn the child report FES, there is one consistent pattern of correlations, that between pain frequency and three types of family functioning. Pain frequency correlates negatively with Intellectual/ Cultural orientation ($r=-.26$, $p < .05$), with Control ($r=-.24$, $p < .05$) and with Conflict ($r=-.26$, $p < .05$). The indication that there is less pain frequency in families with greater tendency toward expression of conflict is a surprising result, but is consistent with findings in other illness groups (McCubbin, et al., 1982).

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In lcoking at the relationship between support variables and illness severity variables, the use of "cthers" for support (friends, social workers, God) related to more hospitalizations, while the use of other parents of sickle cell disease children related to reduced pain intensity. As would be predicted, there was a significant correlation between age of diagnosis and use of medical personnel, with early diagnosis leading to greater support utilization from health service providers.

Slide 9

As with adjustment, severity of illness measures show some significant relationship with the character of the caretaking experience. Specifically, frequency of hospitalization and emergency room visits is significantly correlated with being cared for by "others". That is, when "friends" or "baby sitters" stay with the patient when he or she is alone, there is an increase in number of hospitalization ($r = .28$, $p < .01$) and E.R. visits ($r = .24$, $p < .05$). There is a significant negative correlation between caretaking by "others" and "pain intensity" ($r = -.26$, $p < .05$) consistent with reported findings (Hurtig & White, 1986) that pain intensity differs from other aspects of illness severity. The amount of time spent alone shows a significant positive correlation with age at diagnosis, indicating that the earlier diagnosed patients spend less time alone, partly a function of age.

Separate analyses of variance by family type, family income type and SES revealed no significant effects. In terms of SES the absence of effects may be due to the small variance in the sample.

Discussion

Our findings on family environment indicate that, with a few noteworthy exceptions, the sickle cell patients and their families interviewed do not differ significantly from the normative sample in their experience of their family. The high levels of achievement, moral/religious, organization and control emphasis are descriptive of what has been labelled a "normative-authoritarian factor" (Engfor, et al., 1978) Moos & Moos, (1981) in a

separate analysis of ethnic minority families in their normative sample, found them to be "....more structured, with more emphasis on achievement, moral/ religious emphasis, organization and control....". This pattern is consistent with that noted in our sample. While we had considered that the lower SES sample may be the major factor contributing to the pattern noted, Moos & Moos were drawing from predominantly upwardly middle class groups. A more extended sample with greater range is currently being evaluated.

The analyses support the first hypothesis, that family environment and family/social support significantly impact on the adjustment of sickle cell disease children and adolescents. Comparisons with the norms for the clinical populations on the CTP and CBCL have suggested that pediatric sickle cell disease patients have slightly lower levels of personal and social adjustment and slightly higher levels of behavior problems in specific behavioral areas (Hurtig & White, 1986). However, when analyzed in relationship to illness severity, it was found that illness factors did not contribute to these adjustment disturbances. This study indicates that socio-environmental factors, primarily the family environment, and to a limited degree the type of family support available and the person who takes care of the ill child, do contribute to the patient's level of adjustment. There is little surprise in the fact that cohesive families with high degrees of concern and commitment, helpfulness and empathy are most strongly related to higher levels of adjustment, or that conflict, the open expression of anger and aggression, is negatively related to higher levels of adjustment.

The strong pattern of relationships in all but 3 of the 9 FES sub-scales is evidence of the close ties between family climate and adjustment.

Despite the differences between the child and parent reports, the same scales lack relevance for both groups: expressiveness, achievement, and with only one significant correlation from the children's report, control. The results clearly indicate that for the families of this sickle cell sample, closeness, support, the encouragement of independence and feelings of autonomy and competency, active social, intellectual, cultural and recreational participation, an emphasis on ethical and religious issues and the presence of organization and planning, all contribute to better adjustment socially, personally and intrapsychically. Most of the scales which are relevant also contribute to school performance and intellectual achievement. Predictably, intellectual/cultural orientation is most contributory. Achievement, the climate which emphasizes grades and competition, does not relate to either intellectual achievement or school performance. This supports the clinical approach which recommends reducing competitive pressure and increasing support and interpersonal interactive behaviors in order to accomplish achievement orientation indirectly.

The role of social support is more equivocal, given the limited exploration of this issue in our study. The findings that the patient's personal adjustment is significantly higher in families with a broad support network, where relatives in addition to immediate family members are available for support, is consistent with the social support literature (Haggerty, 1980). An analysis of the relation between family support and family climate revealed higher levels of conflict in those families who go to neighbors and to church for support. Those families who did reach out to church and other

sickle cell families may have been those with the most need, in terms of psychosocial stress and illness severity. The lower school performance in those children whose parents reach out to "other" sources of support, other sources being friends, social workers and God, may be a function of school absence secondary to illness factors. The findings regarding caretaker of the sickle cell child during illness appear paradoxical, but are actually consistent with clinical experience. Caretaking by siblings ("immediate family member other than parent") is problematic for children who are vulnerable to pain and complications and may need quick, emergency treatment. Often these caretakers are in the same age group as the patient. The presence of an older caretaker (other than parent or immediate family member, usually grandmother or aunt), appears to contribute to adjustment. Caretaker availability and support are two aspects of the same issue, protection and security, and are also linked to the cohesion aspect of family climate, which was found to relate positively to adjustment.

The hypothesis that illness severity and familial/social forces would be closely related was generally weakly supported. The sickle cell patients in Active-Recreational oriented families have more frequent hospitalizations, E.R. visits and pain crises. This is consistent with the nature of the illness, with pain crises frequently brought on by high levels of activity. The negative relation between pain frequency, conflictual, intellectual/cultural, and controlled family types can be viewed from a coping perspective. Jackson (1970, 1977) has noted the significant role that family rules play in the adaptive functioning of the family. Control is defined as "the

extent to which set rules and procedures are used to run family life" (Moos, 1941). Lewis, et al, (1976) have also pointed out that the structural rigidity of families is related to quality of adaptive functioning, with adequate families having rigid structures, optimal families having flexible structures. Lewis' study was done on intact, middle class families. Our data suggests that for minority, lower-class families dealing with severe chronic illness in addition to the socioeconomic stresses of their status, relatively rigid structures are effective in reducing the frequency of pain crises in children. How intellectual/cultural orientation contributes to preventive or buffering effects is not as clear, although it is possible that this family style represents the higher level functioning families able to utilize systemic social supports not measured in our study. While conflict and poor adjustment are related, conflict and reduced pain are also related, a surprising finding. Conceptually, one would expect that more frequent pain crises would contribute to family stress and potentiate conflict. It may be that the presence of frequent pain crises reduces conflict by focusing the family on major concrete problems which require organization, outreach and support. A less benign interpretation would be that conflictual families are less likely to attend to pain and thus underestimate its presence and frequency.

The different pattern of relationships which social/familial factors have with adjustment as opposed to illness severity suggests that these factors cannot be considered mediators between the two variables. A linear regression analysis with added factors may begin to explain the complexity of the relationship. Among the accitional factcrs we are exploring in cur

ongoing study are external stressors, such as life change events (Dohrenwind & Dohrenwind, 1974).

In conclusion, the data support clinical wisdom which recognizes the crucial role of social/family factors in children's adaptation to the illness experience. Certain types of family environments are more protective than others in buffering the sickle cell child against the multiple stresses of the disease. Through understanding the nature of the protective function of the family, schools, community groups, and medical centers can design their programs to enhance adaptive functioning for the child and for the family. Children whose families organize, structure and place clear limits on their members are less likely to have adjustment problems, and are more likely to do better at school. Children who are left with other children when they are ill or who spend much time alone suffer from the effects of that experience. Children whose families organize themselves around external sources of support and stimulation, whether they be cultural, recreational or religious, are more resilient in the face of the illness experience, independent of the degree of severity of illness.

In the absence of comparison groups, we cannot conclude that these findings are characteristic of sickle cell children as a result of their disease identity. Despite the contribution that illness, physical limitations, and developmental delays make to psychological adjustment, other variables may be more potent, depending on the protective or coping mechanisms which are available to the child. Further studies are currently being developed to compare the sickle cell sample with other chronic illness groups and with uninvolved children, in order to weigh the contribution, if any, that

sickle cell disease as a specific type of illness in a specific population group, makes to the relationships discussed in this study. In addition, a longitudinal study of a small group of the younger children is in progress, with 8 and 10 year olds being reevaluated after two years. Despite the findings of no age differences in the cross-sectional study reported on in this paper, a developmental approach may serve to illuminate some of the areas we are exploring, particularly the impact of puberty on the disease process as it relates to adjustment.

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Dependent Variables:

Illness Severity:
- Frequency of hospitalization in last 4-year period.
- Frequency of emergency room visits in last 4-year period.
- Frequency of pain crises.
- Intensity of pain crises.
- Age at diagnosis.

Psychological Adjustment:
- Intellectual Achievement (short form WISC-R)
- Social Competence (CBCL)
- Internalizing Behavior Problems (CBCL)
- Externalizing Behavior Problems (CBCL)
- Personal Adjustment (CTP)
- Social Adjustment (CTP)
- Self Concept (Piers-Harris)
- School Achievement (Questionnaire)
- Peer Relations (Questionnaire)

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Independent Variables:

Family Environment Scale: Sub-scales (Family "Climate")

Cohesion	Intellectual/Cultural Orientation
Expressiveness	Active/Recreational Orientation
Conflict	Moral/Religious Orientation
Independence	Organization
Achievement	Control

Family Type: Single-parent, Married couple, Step-parents, Foster family, Grandparents

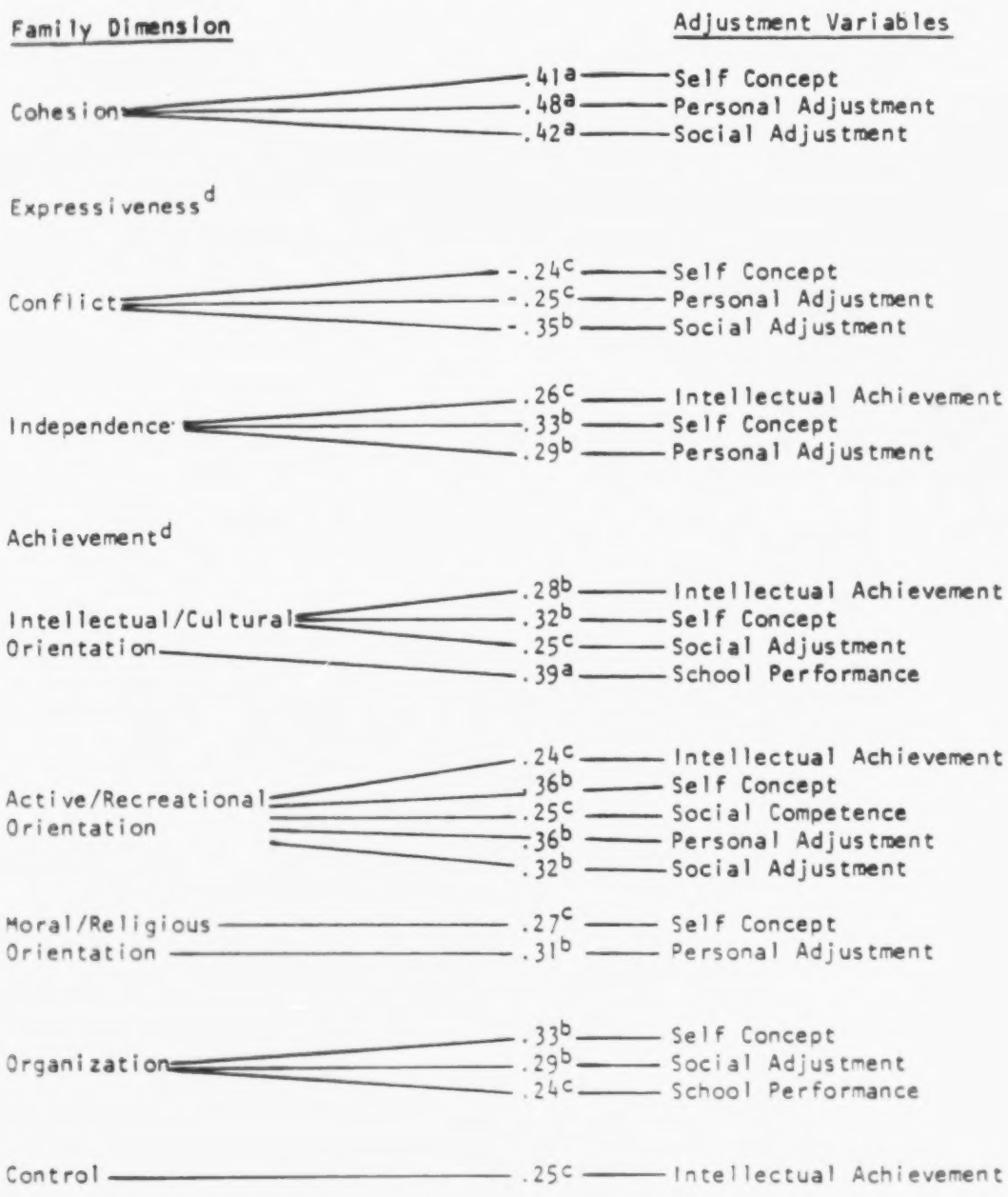
Family Income Type: Working father, Working mother, Public assistance, Disability

Support System Utilization: Immediate nuclear family only, extended family, medical or social service personnel, neighbors, none.

Caretaker of Child when Ill: Parent, alternative immediate family member, extended family member, neighbor, and amount of time spent alone.

Slide 2

- Correlation between Adjustment Variables and Children's Perception of Family Organization (FES)



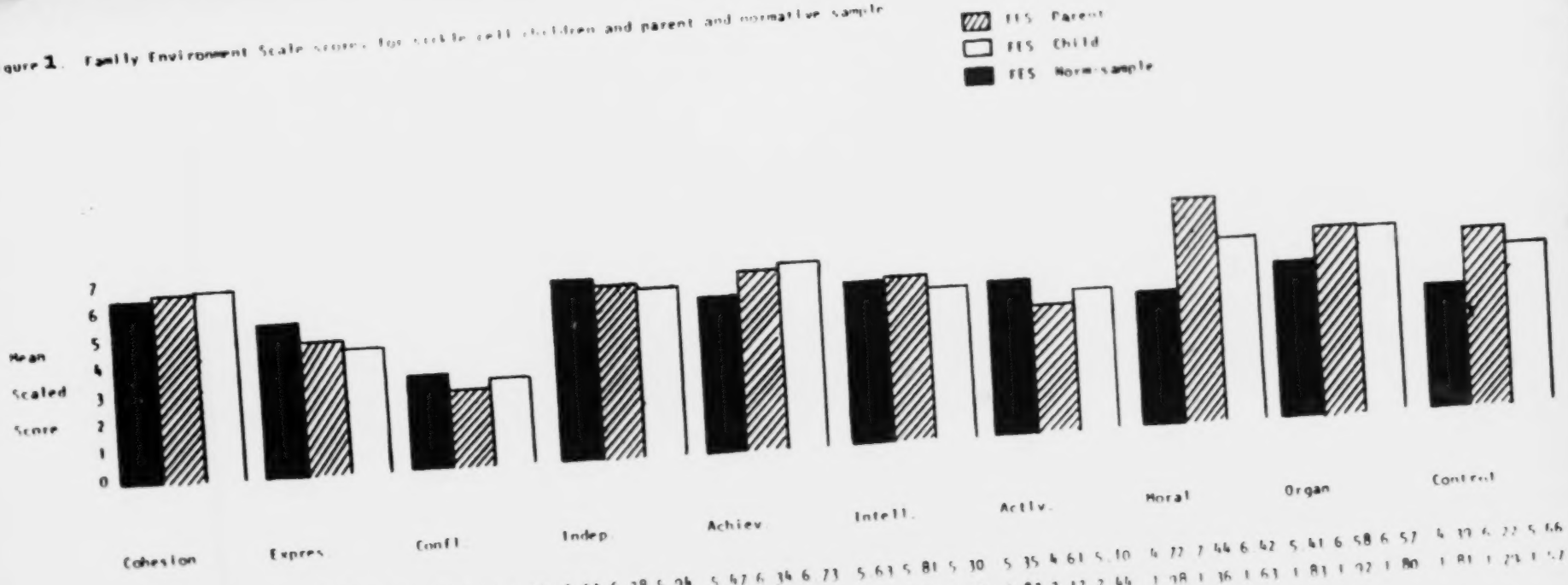
a. - $p < .001$
b. - $p < .01$
c. - $p < .05$
d. - No significant correlation

Correlations between Adjustment Variables and Parent's Perception of Family Organization (FES)

Family Dimension		Adjustment Variables
Cohesion	.31[b]	Peer Relations
Expressiveness[d]		
Conflict	-.30[b]	Peer Relations
	-.34[b]	School Performance
Independence	.33[b]	Self Concept
Achievement[d]		
Intellectual/Cultural	.24[c]	Peer Relations
	.28[c]	School Performance
Active/Recreational	.30[b]	Self Concept
	.28[b]	Social Competence
	-.30[b]	Externalizing Behavior Problems
	-.25[c]	Internalizing Behavior Problems
Moral/Religious	.26[c]	Peer Relations
	-.29[b]	Internalizing Behavior Problems
Organization	-.27[b]	Internalizing Behavior Problems
Control[d]		

a. - $p < .001$
b. - $p < .01$
c. - $p < .05$
d. - no significant relation

Figure 1. Family Environment Scale scores for stable self-children and parent and normative sample



	Cohesion	Expres	Confl	Indep	Achiev	Intell.	Actly.	Moral	Organ	Control
M	6.61	5.45	3.31	6.61	5.47	5.63	5.35	4.72	5.41	4.33
	6.68	4.87	2.85	6.28	6.34	5.81	4.61	7.44	6.58	6.22
	6.69	4.32	3.13	5.94	6.73	5.10	5.10	6.42	6.57	5.66
S	1.36	1.55	1.96	1.13	1.61	1.72	1.87	1.28	1.81	1.81
	2.13	1.68	1.97	1.53	1.30	1.86	2.12	1.16	1.82	1.73
	1.83	1.42	2.18	1.61	1.15	1.53	2.44	1.63	1.80	1.57

Slide 5

Correlation between Adjustment Variables and Social Support

Social Support		Adjustment Variables
No social support	-.27[c]	Personal Adjustment
Immediate family[d]		
Relatives	.25[c]	Personal Adjustment
Medical personnel[d]		
Sickle Cell Center[d]		
Neighbors[d]		
Church	-.25[c]	Self concept
Other parents of Sickle Cell children	-.35[b]	Self concept
Others	-.29[c]	School performance

a. $p < .001$
b. $p < .01$
c. $p < .05$
d. no significant correlation

Slide 6

Correlation between Adjustment Variables and Caretaking

Caretaking		Adjustment Variables
Parent[d]		
Immediate family member	-.26[c]	Externalizing Behavior Problems
Other relative	.25[c]	Self Concept
	.28[c]	Social Adjustment
Neighbor[d]		
Other[d]		
Amount of time spent alone	-.34[b]	Personal Adjustment
	-.32[b]	Social Adjustment

a. $p. < .001$
b. $p. < .01$
c. $p. < .05$
d. no significant correlation

Slide 7

Correlation between Illness Severity Variables and Social Support

Social Support		Illness Severity Variables
No social support[d]		
Immediate family[d]		
Relatives[d]		
Medical personnel	.25[c]	Age at diagnosis
Sickle cell center[d]		
Neighbor[d]		
Church[d]		
Other parents of sickle cell children	-.24[c]	Pain intensity
Others	.24[c]	Frequency of hospitalizations

a. $p < .001$
b. $p < .01$
c. $p < .05$
d. no significant correlation

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Correlation between Illness Severity Variables and Caretaking

Caretaking		Illness Severity Variables
Parent[d]		
Immediate family member[d]		
Other relative[d]		
Neighbor[d]		
Other	.28[c]	Frequency of hospitalizations
	.24[c]	Frequency of Emergency Room Utilization
	-.26[c]	Pain intensity
Amount of time spent alone	.27[c]	Age at diagnosis

a. $p. < .001$
b. $p. < .01$
c. $p. < .05$
d. no significant correlation

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